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ABSTRACT

This booklet was prepared to assist planning and service agencies and personnel with evaluation and advocacy of programs and services for the developmentally disabled. Part 1 of the booklet deals with evaluation, part 2 with advocacy; discussed in both sections are such issues as the legislative mandate, the use of computerized systems, systems development, the role of the professional, and the role of state developmental disabilities councils. (Bibliographies relating to both evaluation and advocacy are included.) (BD)

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The New Jersey Developmental Disabilities Council operates pursuant to State Executive Orders in keeping with the requirements of the Federal Developmental Disabilities Services and Facilities Construction Act of 1970 (PL 91-517) and the Developmentally Disabled Assistance and Bill of Rights Act of 1975 (PL 94-103). The Act provides for comprehensive planning, evaluation, service development and advocacy efforts to meet the needs of the developmentally disabled—persons whose normal mental and/or physical development has been seriously impaired during childhood by mental retardation, cerebral palsy, epilepsy, autism or other substantial disorders requiring similar treatment. The Acts require the existence in each state of a permanent, official planning and advisory council whose functions include: planning, by assessing the needs of the disabled population, identifying gaps in the service system, recommending immediate and long-range service priorities, and developing the State Plan (which is revised and updated each year); coordination of all available service programs affecting the disabled; communications and provision of information; and provision for the utilization within the State of grant monies made available under the Act.

The New Jersey Developmental Disabilities Council fulfills its obligations to handicapped individuals under Section 504 of the Rehabilitation Act.

FOREWORD

The New Jersey Developmental Disabilities Council has prepared this booklet to assist planning and service agencies and personnel in all sectors of the expansive developmental disabilities field in the formulation and implementation of their own roles in respect to evaluation and advocacy of programs and services for the developmentally disabled. While evaluation and advocacy are very different foci of concern and activity in the improvement of services for the developmentally disabled, they are related insofar as both are relatively new and critically important concerns, both have received legislative attention in recent years which mandates action on them, and each in a variety of ways influences the quality and effectiveness of the other.

We have oriented this booklet toward a discussion of issues rather than "how to" guidelines, due to the tremendous degree of variation in the structural, fiscal and programmatic contexts in which particular agencies and personnel must work even within the same region of the country. At the same time, the issues involved in initiating, expanding or modifying effective systems of evaluation and advocacy remain constant regardless of the size, emphasis, location or public or private status of a particular service or program.

In large part, the following text has been based on remarks delivered to the Region II Conference on Evaluation and Advocacy sponsored by the New Jersey Developmental Disabilities Council in 1975, for which we gratefully acknowledge Ronald Neufeld, Co-Director, Developmental Disabilities Technical Assistance Systems, University of N.C.; Max Addison, National Project Director, National Association for Retarded Citizens; Judith Yaskin, then Assistant Public Advocate, N.J. Department of the Public Advocate; Robert Gettings, Executive Director, National Association of the Coordinators of State Programs for the Mentally Retarded; Tashida Mayeda, consultant and contractor to the President's Committee on Mental Retardation; and Seldon Todd, then Program Analyst, H.E.W. Office of Planning and Evaluation and currently Executive Director, American Association of University Affiliated Programs for the Developmentally Disabled.

We also wish to thank the many "pioneers" in these vital areas of activity throughout the country whose sharing of concrete experiences and thoughts about them over the past two years have assisted greatly in bringing those perspectives up to date.

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EVALUATION: The Challenge

An increased emphasis has unmistakably been placed on evaluation of programs in the developmental disabilities field. While there was a time when the very "worthiness" of the developmental disabilities cause was sufficient grounds on which to pursue increased appropriations and increased commitments of the public and private sectors on behalf of this population, several factors have changed this situation dramatically. There is general skepticism across the nation about the value of human service programs, even in areas traditionally taken for granted, which has led to a general questioning of additional expenditures in the human services area as a whole.

There has been a period of tremendous growth in human services, particularly since the intensification of pressure on the part of those needing such services since the early sixties. Such demands have included public funding of services on behalf of the developmentally disabled population. In the area of residential and community programs, some $2 billion are being expended nationally on services to the developmentally disabled. If one includes educational rehabilitation, medical and other services delivered in other settings, the figure climbs to $6 to 7 billion a year. It is entirely appropriate for taxpayers to begin to ask where developmental disabilities programs and services are going.

Further, there has been an astronomical jump in program costs. Part of this has been due to inflation, but a lot of it has been due to improvement and expansion of programs. People are beginning to ask hard questions about what developmental disabilities programs are all about and what the relative benefits are of those additional expenditures. Legislators are becoming particularly sensitive to such questions as it is increasingly difficult to balance increasing demands, however legitimate, with diminishing resources.

All of these factors have led to growing pressure on program administrators to produce sound, defensible data upon which to justify the continuance and expansion of their programmatic commitments. This pressure has led to a proliferation of evaluation models, most of which have been developed within the last ten years. This proliferation of frameworks and instruments for evaluation can be generally classified into four basic approaches:

The accreditation model attempts to assess program quality by

systematically viewing the program against a pre-determined set of operating and physical facility standards. Essential operating criteria or standards for a program are determined by consensus among leaders in the field, then used as a means for reviewing individual programs.

The normative model attempts to assess the extent to which a program has reached its own stated goals. These systems attempt to take an objective measure of the degree to which internal objectives have been met, and assume that those objectives are correct.

The program impact model attempts to determine effectiveness of a particular program or set of programs in respect to its impact on the whole system of which it is a part or the whole developmentally disabled population.

The client-based developmental model focuses on the progress achieved by individual program participants. Based on that assessment of individual progress, one reviews, analyzes and determines the quality of a particular program or set of programs.

All of these approaches play important roles in a comprehensive system for evaluation.

What kinds of evaluation criteria are important? One of the mistakes that can be made is to become "obsessed with data." It is relatively easy to collect all sorts of information within a confined population such as the developmentally disabled, and it is also easy (and often fun) to manipulate that data. One can make all sorts of interesting, but irrelevant, comparisons. Those developing evaluation systems must continually ask, to whom does this data have meaning? Is the appropriate information being collected in respect to what needs to be learned? What is useful to know in respect to assessing program quality, and what is an appropriate expense, both in terms of dollars and personnel commitment, to incur in the process?

Whatever evaluation framework is developed must be able to accommodate and build on existing evaluation systems already in place or being developed in many states. One cannot expect a state to "throw away" several years of effort and several million dollars in development costs for its system because the Secretary of H.E.W., for example, issues a report to Congress saying that another type of system ought to be developed. Whatever system is developed must not only allow for variation in approach, but for continuing change. Not everything is known about the developmental disabilities field, or about the long-range consequences of what is being done.

As experience accumulates and new knowledge is developed, there must be flexibility to make the best of both. At the same time, the overall system must not be so fluid that it lacks continuity from one period or location to another. It should be technically simple, readily adaptable and produce the needed results. It should be based on a realistic assessment of the sophistication of users of the system, so that it can actually be put in place and used. Safeguards on confidentiality of information must be built in, since the collection of data on individual clients will be imperative at some level of whatever system is developed, and their right to privacy must be protected. Such data must not be accessible outside of the limited focus of those who absolutely need to have it.

The system must also be developed cognizant of the resources available within each state for implementation, and it must be compatible with other information systems. Any kind of evaluation system must be affordable and must be able to intersect with other systems. For example, under Title XX of the Social Security Act, each state is developing a client-based file made up of data on the client and his or her progress. Certainly that system should be compatible with any evaluation system for the developmentally disabled, and duplication of efforts and resources should be avoided.

Finally, the system should be modular, to permit a state to enter it at the point at which it is prepared to do so. If one state has done little or no work on an evaluation system, it must be able to start effectively at the "ground floor." At the same time, another state which has been working for several years in the evaluation area must be able to continue from that point. In short, the goal should be a nation-wide program evaluation system which utilizes present levels of skills, experience and resources to the maximum, while minimizing, if not eliminating, cross-purpose, regressive and unrealistic efforts.

EVALUATION: The Legislative Mandate

Section 110 of P.L. 94-103 (Developmentally Disabled Assistance and Bill of Rights Act) requires the federal government to design an evaluation system in two years after the date of enactment, and implementation of this system by the states within two years after this design is completed, in order to retain eligibility to participate in the

Developmental Disabilities Program. The law also requires H.E.W. to send the design to Congress for review. Section 204 of the Quality Assurance part of the Act requires H.E.W. to review regulations for all H.E.W. programs involving the care of the developmentally disabled in institutions or community programs, and to carry out these studies by contract. Contracts have been made with organizations outside of H.E.W. to carry out the major portion of these studies, and their reports will be submitted to H.E.W. for analysis and staff input before final conclusions and recommendations are formulated.

Very little had been learned from evaluation efforts prior to the enactment of the Developmental Disabilities Act. One of the conclusions of an initial survey was that there existed no clear definition of objectives for developmental disabilities programs. The research team also interviewed federal officials, state officials and program administrators in the developmental disabilities field, and found that they were in overwhelming agreement about the lack of—and need for—a clear statement of objectives. As evaluation is dependent upon objective statements, and since assessment must be determined by comparing program information with such objectives to determine progress or effectiveness, this was indeed a serious state of affairs.

At the same time, the research team found that there were a number of projects which had as a stated goal identification of the developmental progress of disabled individuals, and reviewed in their report systems that were operational in a number of states. Flowing from this came the idea of using the progress of individuals as criteria for evaluating programs as mandated by the law. Senate staff reasoned that the ultimate purpose of federal and state programs in the developmental disabilities field is, after all, to help individuals; if it is possible to measure developmental progress achieved by individuals, it seemed reasonable to use such a measure to assess the effectiveness of government expenditures. This led to the conclusion, expressed in draft bills, that an evaluation system should be modeled after those existing in several states which placed client progress at their base, and which could be applied not only to effectiveness of state developmental disability dollars but all federal programs.

H.E.W. personnel, however, rapidly found that it would be impossible to go that far. First, no existing client tracking systems were operating on a statewide basis. Second, the cost factor was prohibitive to many states. Third, there was an obvious problem in determining precisely what the relationship is between individual client progress and program effectiveness—as well as the nature of "client progress" itself. Fourth, serious questions arose concerning the inference from

an aggregate of individual progress conclusions, generalized conclusions about the progress of the disabled population as a whole. There has simply not yet been enough experience and systematically accumulated data to be able to evaluate a particular service activity on the basis of the progress of the developmentally disabled individuals involved in it, due to the great variability among both individuals and programs.

Resulting legislation requires that evaluation be based primarily on data obtained from individualized written habilitation plans. This appears to mandate a client-based developmental model, or, if a multi-dimensional evaluation model is found to be more appropriate, that such a system must have the progress of the individual client at its base. In reality, however, individual habilitation plans are often little more than pieces of paper to which people pay little attention. It is too easy to focus concern on whether there is a nice, neat, official piece of paper in the client's file rather than how or if it is actually used in service planning and delivery. Unless that piece of paper has a direct and active role in what actually *happens*, it is certainly not going to be of much use for genuine evaluation purposes.

The legislation also requires the evaluation system to include specific criteria by which the developmental progress of the individual can be measured, raising further questions related to standardization. One of the major problems confronting the developmental disabilities field is the utility—and accuracy—of the "developmental milestones" that are built into this type of system. Many would suggest that one cannot develop any kind of criteria for such a complex mix of people as are currently subsumed under the developmental disabilities label. Further complicating the problem is the need for a "data flow mechanism" that can be responsive to variation in the data needs of personnel at different levels both within and outside of the service system.

EVALUATION: The Use of Computerized Systems

When one begins to consider the developmental progress of individuals, the volume of information required is enormous, encompassing data on behaviors, personal history, evaluations, diagnoses

and activities. One must review what has happened prior to the time the individual entered the service system, where the individual has been placed within that system and how well he or she has done in those service programs. It is no wonder, particularly given the size of developmental disabilities service consumer populations, that many in the field are inclined to favor computerized data processing systems to accomplish the many tasks related to planning, evaluation and simply keeping track of where people are and how programs are functioning.

However, if the sheer volume of information is to be accepted as a built-in problem, and computerized systems accepted as the most efficient way to resolve it, additional problems become apparent. It is not enough to offer a mechanical answer to what is far from a problem of mechanics. Data collection "management" is one thing, but its purpose, or what the data is being collected *for*, is quite another. Clear policy decisions must be made, and programs for computerized systems designed accordingly, in respect to confidentiality, what variables are useful to correlate, and what objective standards are going to be utilized in the process by which data retrieved from the system is applied. Without clarity on these issues, what can easily result is the production of unrelated, incoherent, aggregated "facts" not only devoid of meaning but dangerously open to misuse and (even if inadvertant) irresponsible manipulation.

On the one hand there is a developmental sequence that is standard, or "normal," against which one can compare the developmental level, or "progress," of an individual. On the other hand there is a myriad of program and service types designed to help the individual achieve the next phase of development. Problems can arise in the first instance due to the many types of development—physical, psychological, linguistic, social and emotional—which for the "normal" individual do not appear as distinct, or separate, because the development process is fairly even and rapid. For the disabled individual, however, it is often crucial to separate these types of development, trace any differential rate of progress that may occur among them, and recommend specific types of services and programs related to more than one.

In the second instance, there are often many differing approaches available to assist the individual in a particular type of development: a structured, long-term infant stimulation program, for instance, with a professional staff and highly equipped facility, or a home-based program with parents and other caretakers who have received appropriate paraprofessional training. The process which prescribes one as opposed to the other is often a subjective one on the part of a coun-

selor, diagnostician or social service caseworker, or is proscribed by factors such as program availability, cost, location or parental preference. Which individual can benefit most by which type of program is a delicate conclusion to reach, and cannot be determined by the logic of statistics alone. The fact that a child in a home-based program may develop at an equal rate to one in a sophisticated institutional program does not necessarily indicate that funds supporting the latter would be more fruitfully allocated elsewhere, although it may indicate that a reassessment might be made of any policies blanketly favoring one approach over the other.

Tremendous variation in needs, capacities and responses of individuals with the same disabling condition, as well as in family atmosphere and situation, make it difficult to evaluate progress or services in terms of numbers alone. Objective indications of *lack* of progress, too, particularly as it relates to service programs, must be examined not only in terms of curves on a chart or test scores, but factors such as barriers not always accounted for in what data has been *chosen* for recording, such as availability of transportation on a regular basis, or intervening conditions which might interrupt the rate of progress of an individual or group of individuals.

It must also be understood that the information which is retrieved from a computerized system is not, in and of itself, conclusive. More often it produces a *starting point* in the evaluation process, offering hints on where to look more deeply for information that can provide an accurate assessment of program quality.

Once an individual or program is "evaluated," there must also be a mechanism for acting upon that evaluation beyond reporting it to funding sources. The computer can only offer the information, and, if programmed appropriately, sort it in ways that can facilitate its use. Mechanisms must also be developed, however, for translating this information into action at the service delivery level, such as moving clients from what have been found to be inappropriate programs, in the individual case, to alternative approaches, or for providing supplementary assistance in program areas where external barriers, rather than internal programmatic faults, have been identified as inhibiting maximum effectiveness.

EVALUATION: Overview of System Development

Since the passage of the 1975 amendments, a great deal of progress has been made in developing methods for accomplishing many kinds of evaluation tasks at many different levels of the service system. Consultants are actively engaged in integrating and analyzing the results of the long-term studies accomplished during this period to develop an effective model on a national level.

Florida's Division on Mental Retardation pioneered in the development of a "Behavioral Assessment Scale," based on the AMD Adapted Behavior Scale but modified in several important ways to meet the particular evaluation needs of programs for the mentally retarded in that state. Louisiana has also modified the AMD scale for its own use in program evaluation. Minnesota has developed a "Developmental Program System" based on specific criteria for measuring client progress which is then used to measure program effectiveness, and this system has been adapted for use in Missouri, also. Texas has adapted the "Behavioral Characteristics Profile" developed by the Santa Cruz, California, school system for use in defining behavioral characteristics for comparative purposes for its own evaluation system. Connecticut now uses a computerized management information system, called PLACE, which is designed for evaluation based on individual habilitation plans. Indiana now uses PAC, a system which originated in England and is also based on individual client progress. New York is just completing a three-year study supported by Developmental Disabilities funding to develop a client-based information system based on standardization of behavioral assessment objectives.

By far the most ambitious effort in this area has been the multi-dimensional Individualized Data Base (IDB) study undertaken by the UCLA Neuropsychiatric Institute at California's Pacific State Hospital. The project was specifically charged with analyzing and responding to the new federal evaluation requirements, and exploring the "critical technical issues associated with the evaluation of developmental disabilities services based on changes in the adaptive behaviors of children, youths and adults." The first three-year phase of the project, in which data from nine states was utilized in develop-

ing a model for data collection systems, has been completed and the second three-year phase has begun. Already, Virginia and New Jersey have adopted the IDB forms developed by the project, and are establsihing compatible (though independent) evaluation systems based on them.

Despite the variations that are found among the current client-based evaluation approaches, there is a common philosophical framework that is built into all. First, they are all based on the concept and belief that it is possible to aggregate individual assessment data and get a meaningful quality assessment of programs for the developmentally disabled. Second, they are also all in one way or another dependent upon the client's individualized habilitation plan. Third, they are all built around the concept of a goal-oriented system of providing services and using the results of the "output" from the system to measure progress. Finally, they have all developed standardized, specific developmental criteria against which to assess client progress.

EVALUATION: Role of State DD Councils

State DD Councils face three primary responsibilities in respect to evaluation: 1) development and implementation of an effective in-house system for continuing assessment of their own activities and grant programs, 2) participation in the design and formulation of recommendations for a comprehensive national evaluation system, and 3) coordination of and assistance to developmental disabilities service agencies in implementing whatever comprehensive system is adopted on the federal level.

As state Councils function, due to their representative composition, as a natural forum for exchange of experience and insight among service agencies, they can easily serve as a center for such interaction on the specific issue of program evaluation. Not only can information be gleaned concerning the utility of different types of systems in specific program contexts (as all have had to be involved in evaluation efforts of various kinds), and the status of existing client information systems within the state, the Council can also serve as a conduit of

similar information from other parts of the country and the results of research with a national scope.

All Councils, whether by subcommitee, contract or staff assignment, should already be involved in developing and/or implementing a system for evaluating its own efforts. Experience gained in this process should provide a valuable point of departure in formulating recommendations for incorporation of successful features which emerge into possible formulations for a large-scale system. All Councils should also insure the development and use of a meaningful program evaluation mechanism by the agency which administers the Developmental Disabilities Service Grant Program.

In their role as "collective advocates," state Councils should encourage and facilitate the development of effective evaluation policies and mechanisms by service providers and planning agencies. State Councils are in an optimal position to provide information and coordination to such efforts.

Finally, each Council should include evaluation of the impact of service programs on the developmentally disabled population as a whole within its annual planning cycle, as part of the process of data collection and analysis.

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ADVOCACY: The Challenge

Current legislation is genuinely sensitive to the needs of developmentally disabled citizens, one of which is advocacy. An advocate, simply defined, is someone who is trying to maintain or promote a cause. From an individual perspective, advocacy is acting in behalf of, or pleading a cause for, someone else. The basic goal of developmental disabilities advocacy activity is to improve the quality of life and protect the legal rights and status of an individual or group of individuals with developmental disabilities. Many problems exist in the service delivery system that have given rise to the need for advocacy on behalf of the developmentally disabled, particularly as members of this specific population are frequently unable to express themselves in respect to the fulfillment of legal rights and entitlements.

The past twenty years have brought about unparallelled growth and expansion in the field of human services generally. In many states, this growth has resulted in the corresponding development of organizations and agencies at the local, regional, state, multi-state and national levels. To a citizen at the local level, this bureaucracy, in the private as well as the public sector, often resembles a large onion: no matter how many layers are stripped away, there always seems to be yet another layer to contend with. A person attempting to "strip away the layers" is likely to be driven to tears before an accountable agent is found.

Some people refer to this bureaucracy as a "system" or "machine." This analogy is weak in many instances, as both terms imply a functional relationship between the various parts of the whole. However, as one crosses the boundaries between bureaucratic units and levels in the service delivery system, he or she is often likely to experience a great deal of fragmentation, repetition and lack of communication, instead. At the federal level, one faces the piece-meal evolution of legislation, followed by confused agencies trying to implement this legislation while at the same time maintaining some coordination and communication between the many parts of an enormous service structure. Coordination and communication seldom improves greatly at the state level. State agencies spend much of their energy in political warfare between each other, in activity aimed at gaining support for their own programs from governors and legislators. Similar interagency warfare and "turf defense" occurs at the local level, where individual service units are even more vulnerable to the vagaries of

budget and policy decisions formulated by strangers far away, inaccessible, and often unidentifiable. Meanwhile, professionals disagree on both theoretical and practical levels on everything from definitions to eligibility to strategies, to the point where many providers and seekers of service remain confused about what might be right, good, adequate, appropriate or best. These conflicting viewpoints are played out in conflict between service providers at the local level. In some instances, local agencies compete for control over the same client populations; in other instances, a particular group may be excluded from the preferred client population. In either case, many citizens are left with their needs altogether unserved.

As genuine attempts are made to improve human services and the haphazard way in which they are often arranged, agency upon agency has been created, followed by "umbrella" agencies. The ultimate loser is the citizen who needs and is entitled to service but cannot gain access to it. Human service arrangements have become so large and complex that even the most highly skilled individuals need help in picking their way through the maze that constitutes the delivery system. At the same time, the service system has become so large and, often, so detached from the clients it is supposed to serve, that service personnel, too, are increasingly confused and frustrated about their roles. The more paperwork they are required to do, the more cut off they are from the clients. Meanwhile, the largest proportion of available resources seems to be absorbed in maintaining structures that seem to exist in and for themselves.

Advocacy calls for change in the human service system, in order to render it more responsive to an individual's needs. To accomplish this, the advocate must be able to muster power. Advocates sometimes create their own organizations that take on the characteristics of a social movement. Indeed, advocates often resemble civil rights leaders, in that they represent a minority population whose basic human rights and needs are often ignored. If the voice of this minority population is to be heard in the continuing flow of the political and bureaucratic stream, then advocates and disabled citizens must organize and present a strong, unified front.

There is always a great deal of resistance to change. Unless there is cooperation, organization—and overlap—between advocates, the developmentally disabled, citizen and parent organizations and public and private service providers, probabilities for success are minimized. Given the scope of problems in the human service delivery system, specific and effective strategies for advocacy must be developed.

It is particularly important to clarify what is being meant by "ad-

vocacy" from situation to situation, as it may refer to a variety of foci, each involving very different personnel and requiring very different skills and expertise:

Citizen advocacy usually involves a one-to-one relationship between a disabled individual and a volunteer advocate who assists directly in negotiating with the service system. It may, however, also involve the participation of community people, in a citizen role, in efforts to bring pressure on the system to encourage change.

Legal advocacy involves professional representation of the legal interests of a disabled individual or the disabled population as a whole, in litigation where rights are felt to have been violated or are in need of judicial clarification, in legislative efforts to correct, extend or improve services or legal status, and in administrative procedures within the system itself.

System change advocacy often involves efforts on the part of citizen and legal advocates, but is specifically directed toward improvement of the existing system of services or administrative procedure associated with it. Further, both citizen and legal advocates may be engaged in efforts on behalf of a developmentally disabled individual (sometimes termed "case advocacy") or efforts on behalf of the developmentally disabled population or a sector of it as a whole (sometimes termed "class advocacy").

Absolute statements about what an "advocate" ought to do or focus upon are, therefore, inappropriate. Because of its many dimensions—and the legal and moral imperatives of each in fully representing and protecting the interests of developmentally disabled citizens—an effective statewide advocacy system must include and allow for successful coordination of components which concentrate separately on each of these areas of emphasis.

ADVOCACY: The Legislative Mandate

Section 113 of P.L. 94-103 requires each state and territory to plan and implement a statewide system of advocacy for the developmentally disabled in order to remain eligible for federal funds for developmental disabilities programs. While advocacy efforts are generally thought of in terms of a community-based volunteer advocate acting on behalf of the disabled individual, the new law specifies that a viable

statewide advocacy system must include "legal" and "system change" advocacy as well as "citizen" advocacy. Such a system must necessarily include many levels and types of activity, involving a broad range of both the lay and professional communities. At the same time, all of these elements are designed to accomplish two primary advocacy goals:

1. Representation of the interests and protection of the rights of the developmentally disabled population as a whole in the legislative, executive and judicial spheres, from the state to the local level, in both the public and private sectors, and

2. Representation of the interests and protection of the rights of the developmentally disabled individual in his or her immediate relationships with the community as well as the legal, political, economic and service delivery systems.

Such interests and rights in respect to services are broadly defined by Section III as:

1. The right to "appropriate treatment, services and habilitation;"
2. Design of treatment, services and habilitation so as to "maximize the developmental potential of the person" and do so "in the setting that is least restrictive of the person's personal liberty;"
3. Obligation of state and federal government "to assure that public funds are not provided to any institutional or other residential program" which fails to provide services appropriate to the individual's needs, to meet specific standards of safe and humane care, or to protect the civil rights of the individual;
4. Obligation of all programs to "meet standards which are designed to assure the most favorable outcome for those served," regardless of size or arrangement, and including realistic appraisal of the potential for appropriate service before acceptance of an individual into such programs.

The statewide advocacy system may or may not be designed and incorporated into the state governmental structure, but it must be able to seek both judicial and administrative redress, and be independent of any state agency which services the developmentally disabled. It is precisely these characteristics which have created the most serious problems for many states in both developing and implementing effective advocacy systems. Lack of direct administrative control by any established service agency, and ensuring the ability to bring litigation against state agencies and personnel, have rendered full compliance with this legislation a deeply threatening prospect to powerful sectors within many state governments. In a very real sense, it will still take

a great deal of effective advocacy activity to see that this critical component of the Act is enforced.

ADVOCACY: "Internal" vs. "External" Approaches

Recent advocacy activity that interacts with the service delivery system has resulted in two conflicting viewpoints. One argues that the only kind of advocacy that can be effective is "external" advocacy, which operates to bring pressure on the service delivery system from outside and is supported from outside resources. The other argues that "internal" advocacy, which is supported by and works from inside the system, is a superior approach. When the strengths and weaknesses of each approach are considered, distinct characteristics emerge:

INTERNAL ADVOCACY

An internal advocate is one who is supported by the system which he or she is trying to change. Proponents of internal advocacy believe that the system needs reform in order to most effectively meet the needs of those it was designed to serve, and that this can be accomplished most successfully from inside that system. Internal advocacy is committed to the identification of individuals whose rights and needs are not being acknowledged by the system in which the advocate is employed. The advocate's work, then, consists of activity directed toward changing the system to be more responsive to the individual client. Internal advocates try to negotiate with service providers and policymakers, avoiding confrontation where possible.

Critics of the internal advocacy approach argue that it cannot possibly work, as it is difficult to "bite the hand that feeds you." Such critics are concerned that when system maintenance or staff interests conflict with client needs, the internal advocate will, voluntarily or not, compromise the interests of the client. Ideally, an advocate always negotiates in the sole interest of the client. It should, simply, be recognized that at the point that a person fails or chooses not to promote the best interest of a client, whether as part of an internal *or* external advocacy effort, that person ceases to be an advocate.

To the extent that an internal advocate can resist being "co-opted" by the system, there are some strong advantages to advocating from within. For example, advocacy aimed at making service more accessible to a client often requires detailed knowledge of the system, its organization and its resources, and such information is much easier to acquire from within the system. Similarly, accurate data concerning program weakness and abuse of clients can be most readily obtained from within. Another advantage to internal advocacy is that financial support is relatively stable. Such stability allows the advocate to concentrate on advocacy activity without expending a large proportion of energy on financial survival. Further, familiarity and working relationships already established between advocacy and administrative personnel within the system can provide a fruitful head start in negotiations not enjoyed by "outsiders" in an essentially adversary role.

EXTERNAL ADVOCACY

External advocates are supported by non-system resources and are not accountable to persons within the system. The external advocate tends to be viewed as an adversary of the system. Proponents of external approaches tend to view the system and all of its parts as evil. When insensitive system arrangements are encountered, the external advocate may be inclined to promote dismantling of the entire system, and may often feel that negotiation is a waste of time, moving quickly to confrontation or appeal to legislative and judicial authority for imposition of the desired change.

The primary advantage of external advocacy is its independence from the system, and resulting theoretical absence of any vested interest in its maintenance. The external advocate is less likely to be co-opted, whereas the internal advocate relies on the ability to negotiate successfully in an atmosphere of cooperation with other elements within the system. The external advocate can bring coercive pressures to bear, such as the threat of court action, exposure through the communications media, and mobilization of parent organizations and political parties.

The greatest disadvantage of external advocacy is the possibility of limited access to the environments in which the clients are actually served, and distance from the personnel in control of them. External advocates must often largely rely on information from secondary sources, which can be vague, misleading, or even faulty. Financial instability, and the particular difficulty of generating private funding sources for an often controversial activity, also create serious problems for the external advocate. In the same sense that the internal advocate

may be led to compromise to maintain a viable position within the system, the external advocate may easily be led to similar compromise for the sake of public relations. External advocacy programs may also be faced with temporary and sporadic leadership and personnel.

These are, of course, contrasting, generalized models. There are, more often, combinations of the two in place with varying degrees of emphasis.

Common sense should indicate that both types of activity, and a good deal of cooperation between them, are needed for the maximum success of each and maximum benefit to the client. Further, the success of all three advocacy dimensions—citizen, legal and system change—depends on the existence of and cooperation between both internal and external approaches.

It is important to recognize that while a large service bureaucracy may alienate its members from individual clients who need service, there are many benevolent persons in the system whose sensitivity and commitment to clients have not been dulled. These are, in a sense, "natural" advocates within the system. Too often, external advocates with an adversary perspective isolate themselves from discovering and establishing relationships with these natural advocates. With no connections or allies within the system, the external advocate is ultimately excluded from opportunities to affect system-level change. Without concurrent pressure from the community and policymaking institutions, resistance to internal efforts remains effective despite challenge from within.

For both approaches, there is the danger that attempts to win a decision in the courts or policymaking body will lose sight of the welfare of the individual client for months or even years in the process, even though in long-range terms the activity may have positive impact on the lives of a large number of people. When an advocate becomes so enmeshed in the role of system adversary or the imperative of system change, it is often possible to become preoccupied with the struggle itself, losing sight of its purpose. The balance between effective long-range change efforts, in which both client and advocate can easily become "lost", and sporadic, ill-coordinated short-range efforts, in which little is accomplished even in immediate terms, must be sought regardless of style, scope, perspective or approach. Both internal and external advocates are trying to resolve the same kinds of problems. They must not become, as many tend to forget in the context of their day-to-day activities, adversaries themselves.

ADVOCACY: Overview of System Development

LEGAL ADVOCACY

In the field of legal advocacy, important gains have been made in the form of laws and precedents, particularly in the areas of rights to treatment, education, employment, alternative housing types and barrier-freedom. Structures for the provision of legal representation are still being developed in many states, as well as effective methods for assisting public and private service providers in understanding and complying with new laws and regulations.

Activities of statewide legal advocacy agencies include investigation of complaints, representation of developmentally disabled clients in court and administrative hearings, initiation of "class actions" on behalf of the developmentally disabled population as a whole, drafting legislation and regulations, encouragement and monitoring of compliance with the law, development of effective advocacy mechanisms and public education in respect to legal rights, entitlements and redress. Emphasis is also placed on close collaboration with other advocacy machinery in operation in the state, to avoid duplication of efforts, utilize advocacy resources most efficiently, and insure maximum effectiveness of each effort.

While progress in the establishment and impact of such an agency varies greatly from state to state, successful experience in respect to internal organizational structure, location in a state governmental network, systems of funding and methods of carrying out the responsibilities outlined above can be examined and drawn upon to improve the ability of similar efforts in other states to achieve their goals.

Statewide advocacy mechanisms can also meet many related needs. New Jersey's Office of Developmental Disabilities Advocacy, for example, administers a specialized field project to assist both residential facilities and communities in deinstitutionalization and to act to remove statutory barriers to this effort not recognized in preliminary planning but which may become apparent in the actual process. The same Office is also serving actively as a consultant to other state agencies in planning for compliance with Section 504 of the Rehabilitation Act. The Minnesota Developmental Advocacy Project also

trains and provides legal assistance where necessary to "lay advocates" throughout the state who work at the local level to attempt to mediate problems faced by disabled individuals, and has developed extensive training materials for advocacy personnel.

The extent to which a legal advocacy mechanism can pursue such related activities depends largely on available resources. In many instances, categorical grant funds or the cooperation of voluntary agencies have been sought successfully in order to provide specific supplementary or "enhancing" services not subsidized by the operating budget of the advocacy agency.

CITIZEN ADVOCACY

Citizen advocacy, an external, volunteer and individualized approach, was a reality in more than 130 communities in the United States by the end of 1975 and had been implemented on a statewide basis in at least nine states, serving some 5,000 developmentally disabled people. The National Association for Retarded Citizens pioneered in the development and sponsorship of such programs nationally.

Citizen advocacy involves a one-to-one relationship between the citizen involved as an advocate and the developmentally disabled person, who is known as a protege. In this relationship, an advocate defends the rights of and provides practical assistance and emotional support to the protege, within a structured program setting. By "one-to-one" relationship is meant that there are few people that are involved in the ongoing relationship between the advocate and protege and no "middleman" between them. A capable volunteer citizen advocate usually often finds this to be a very controversial issue. The volunteer is basically a person who is sincerely interested in the rights of the developmentally disabled person, and is established in the community with the expectation of being on hand for a long period of time. The protege is a person with any developmental disability who is not capable of adequately or effectively safeguarding his own rights, or independently obtaining the services to which he or she is entitled.

The advocate speaks out on behalf of the protege when necessary in order to insure that the protege is receiving all needed services and that quality services are being provided, and often offers practical assistance in matters of everyday life. The latter may include helping a protege learn to budget, use public transportation or handle other essential tasks efficiently. The advocate often offers emotional support, too, which frequently creates problems in that the roles of "ad-

vocate" and "friend" can easily become confused. Many programs have tended to emphasize the friendship element rather than the aspects of practical assistance or protection of rights in the advocate's activity and perspective. "Big Brother," "Buddy" and "Big Sister" programs more appropriately address the very real need for friendship and social interaction. While an advocacy role may naturally flow from this kind of relationship, or vice versa, it should not be defined by it. "Emotional support" should pertain to offering encouragement or understanding when a developmentally disabled person is in a stressful situation.

A citizen advocacy program requires at least one full time professional coordinator (not necessarily with a health care background) who can locate proteges, assess their needs, recruit and train advocates, and bring members of these two groups together on an individual basis. The matching process of advocate to protege generally focuses on the particular needs of the protege as compared to the availability of time and particular skills, experience and interest of the advocate.

As soon as an advocate and a protege are paired, ongoing support should be available from both the program staff and members of a program advisory committee which gives direction to the effort as a whole, recommends policy, forms a link between the advocacy program and the community, gives it creditability and is equipped to deal with specialized problems when they arise. To serve effectively in these capacities, such a committee should be composed of a cross section of the professional and consumer communities, thus providing a wide range of expertise and perspective to the program's staff for consultation and guidance and to advocates or proteges for counseling where needed.

Without establishment and effective coordination of all three elements—trained volunteer advocates, professional coordinating staff and local advisory committee—a citizen advocacy program can become vulnerable to local political interests, the fears of community residents, and antagonistic rather than cooperative responses from landlords, employers and service personnel.

Other types of citizen advocacy activity are being developed in many areas, applying historical models for political and community organization to the specific interests of the developmentally disabled. Included among these are lobbying for desired legislation or changes in existing legislation, mobilizing pressure on government and the service network for improvement in available services and compliance

with new legislation, and public awareness efforts particularly at the community level. Local groups have also begun to form for the purpose of initiating or facilitating action on specific issues, such as the establishment of a group home in the area, or special education programs in the district.

SYSTEMS CHANGE ADVOCACY

Instrumental in the development of feasible models for system change advocacy has been a five year demonstration project begun in 1972 by the United Cerebral Palsy Associations with funding support by the U.S. Bureau of Education for the Handicapped, the National Institute on Mental Health and the federal Developmental Disabilities Office. Various project sites around the country were selected in order to determine the most effective approaches for various geographic locations, as well as in respect to scope, from community-based to regional, bi-county and statewide structures. Common among all of the project sites and the national coordinating body was the designation of one paid professional staff person ("advocacy coordinator") for each, and its participation in a statewide Advocacy Advisory Council composed of people from various segments of the community and representatives of state agencies.

A combination of advocacy approaches were used at the project sites, coordinated with the citizen and legal advocacy systems already existing in each area. Project efforts included initiating, influencing and monitoring legislation in respect to statewide service programs, organizing affected individuals to take direct and meaningful action which demonstrated their political clout, arranging for people to testify at legislative hearings, encouraging coalitions of voluntary agencies and their members to introduce legislative packages that would benefit the total developmentally disabled population, constant dissemination of information so that as many people as possible could effectively participate in the legislative process, and identifying changes that would be desirable on the administrative system level.

The projects were successful in identifying problems and issues which would be generally confronted by system change advocacy efforts. One project site found that there were many bureaus within the governmental system that had little "pots" of money. If these were combined, the total could support dynamic programming with potential for a wide impact—but the bureaus weren't even aware of each other's existence. As a result, this project assumed a "program brokerage" function. In other areas, projects concentrated on promoting the inclusion of a diversity of consumers and consumer represen-

tatives in the decision-making process. These projects found that while many service providers spoke of a "diversity of consumers," in fact most participating groups were homogeneous: predominately white, male, affluent, influential, and well educated. While more women were beginning to participate, people from low income families, ethnic minority groups, and young parents of very young children were as rare in decision-making roles in developmental disabilities services as other realms of social and political activity. As a result, these became target groups for many project sites. Reaching the traditionally "uninvolved" proved a difficult—and not yet entirely resolved—problem to tackle, as most are not participants in the kinds of organizations traditionally incorporated into the developmental disabilities information network. Most projects began efforts through other kinds of community groups and contacts which could provide the link to these populations, although they were not directly related to the developmental disabilities field.

Many projects provided technical assistance to the established consumer groups, particularly in the use of legal appeal procedures and developing informal "litigation" strategies in respect to administrative appeal within sections of the service delivery systems itself. In California, where the law states that there must be an appeal process in "right to education" legislation, there is also a "zero reject" law. When one group of parents attempted to use the appeal process, it was discovered that the County Board of Education had not set one up as the law prescribed. The parents developed a procedure, gained approval for it, used it and won their case. This particular appeal process has become a model for every board of education within the State of California.

The projects tried to get involved in as much of the initial service planning processes as possible, hiring people with specialized skills in public administration, urban planning, program development and the law as advocacy coordinators. There was no requirement for specialized knowledge of disabling conditions or health services—rather, skills were sought in the areas of mobilizing people, as well as a commitment to the protection of rights and elimination of discriminatory practices.

ADVOCACY: The Role of the Professional

The health or social service professional is an important advocate both within and outside of the service system, as he or she is ultimately responsible for the quality and propriety of services. However, as hard as he or she may try to serve in this built-in advocacy capacity, what seems to be an equally built-in conflict of interest cannot be avoided. On the one hand, the professional, by definition as well as job description, must represent the rules, regulations and existing structure of the system; on the other hand, the same professional must, as a responsible practitioner of a particular professional art, safeguard the rights and interests and provide adequate service for the developmentally disabled person. The balance between the two equally compelling duties is struck in a variety of ways, the emphasis often shifting from situation to situation. The balance, however, is often a tenuous one: too much effort on the advocacy side, and the job, or professional status, can be lost altogether; too much effort on the system-maintenance side, and the interest of the client, or professional integrity, can be lost altogether. In either case, the client loses.

As discussed earlier, effective external citizen advocacy programs need an advisory committee which provides a link between the program and the wider community, and can offer professional expertise when problems arise or when advice on general policies is desired. Developmental disabilities and social service professionals, then, can serve an important function in external as well as internal advocacy approaches in a way that to many can be a far more comfortable, and often more immediately, or visibly, effective, role than one at the system-level. This by no means should discourage or minimize the professional's advocacy responsibility or effort in that system-level role. It can, however, broaden the scope of opportunities for impact beyond the inherent and often frustrating limitations of the immediate practice environment.

Efforts, or support of efforts, within local, state and national professional organizations to assist in the development of effective advocacy mechanisms, to pressure for appropriate system change and to educate members on the theoretical and practical meaning of advocacy as it relates to professional practice can also have far-reaching impact,

while remaining relatively disassociated from the immediate employment situation.

At the system level, in structures which offer few avenues for expression of advocacy positions, the professional can, first of all, initiate or become involved in efforts to establish such avenues. Even where those who recognize the importance of such activities might be in the minority, there are always those few others to identify, communicate and cooperate with in what they can expect to be a protracted, long-term struggle within the system—but one which will never succeed if not *begun*. Secondly, routine advocacy activities can be built into the individual professional's practice on a continuing basis, such as referral of clients who need or might profit by specific types of legal or other assistance to the appropriate public or private agencies which can actively pursue the issue. It then becomes the responsibility of the professional to keep up to date on such efforts in the area, to best advise the client on sources of specialized advocacy help.

The health care, rehabilitation, education or social service professional, then, is able to incorporate many dimensions of advocacy activity into the continuing focus of providing service to developmentally disabled individuals. While scope and emphasis may differ greatly from those of the full time or volunteer legal or citizen advocate, this broad, often relatively quiet, type of activity is essential to the effectiveness of a statewide advocacy system.

All such activity complements—and should be viewed by all people and groups involved in advocacy efforts as complementing—direct advocacy efforts on the legislative service system and community levels.

ADVOCACY: Role of State DD Councils

DD Councils have been in an excellent position to combine internal and external approaches and enjoy the advantages of both. The composition of a DD Council has all of the ingredients for an excellent advocacy mechanism. Furthermore, it is mandated to be one. Already, every state Council has encouraged the establishment of an indepen-

dent "Protection and Advocacy" component within the service structure to administer and coordinate advocacy activities. Effective advocacy activity on the part of DD Councils, however, depends on their ability from state to state to balance this internal, often state-structural component with the consumer or private sector of Council representation.

A DD Council cannot fulfill its potential to function as an effective advocacy mechanism unless there is a genuine coalition of all of the interests represented there. With consumer representatives as external advocates, recognizing the potential of individuals within the system to carry on effective advocacy work, and with state agency representatives and service providers as internal advocates, taking seriously the views expressed by those outside of the system in respect to its real effectiveness, the "best of both worlds" may well be achieved in advocacy efforts through the vehicle of the Council.

Indeed, the function of "collective advocacy" in this sense is a statutorily explicit one for state Councils, and separate from the responsibility of developing a Protection and Advocacy mechanism for developmentally disabled individuals. Moreover, the composition of state Councils, as it includes both consumer and provider representatives, can function as an important link between internal and external advocates as it provides exposure to each other's perspectives and capabilities.

DD Councils must also work directly with the private sector to develop and establish effective citizen advocacy mechanisms, and with the public sector to improve the system of service and to guarantee adequate legal, administrative and legislative representation of the developmentally disabled on both a "case" and "class" basis.

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